

# **Charges for Learning Disability Services in West Dunbartonshire**

**An Independent Review  
by Lomond & Argyll  
Advocacy Service**

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## **Executive Summary**

### **1. Background**

- 1.1 West Dunbartonshire Council introduced charges for some learning disability services in August 2008.
- 1.2 Charges apply to Day Centre/Services (£3 per full day) and Housing Support Services (£20 per week)
- 1.3 175 people with learning disabilities have been affected by the introduction of charges. It is anticipated that charges will generate £123,000 per annum (at 2008 /09 rates)

### **2. Review of Charges**

- 2.1 Following the introduction of charges, West Dunbartonshire Council asked that a review of charges and their impact be undertaken. It was agreed that the review should involve consultation with service users and carers.
- 2.2 Lomond & Argyll Advocacy Service (LAAS) were commissioned to undertake such a review. LAAS is independent of the local authority and has been providing independent advocacy services in West Dunbartonshire since 2000.

### **3. Remit of the Review**

- 3.1 Council agreed that the review should consider on the following issues:
  - Do service users have sufficient means to lead a fulfilling and meaningful life?
  - What impact has the charging policy had on service, including take up?
  - The views of service users and carers

### **4. Methodology**

- 4.1 Learning Disability Services have provided LAAS with a range of statistical and background information to inform Section One of the Review.
- 4.2 Lomond & Argyll Advocacy Service have consulted with thirty-five people with learning disabilities using independently facilitated “focus groups” and individual questionnaires.

- 4.3 Postal Questionnaires were distributed to forty carers/relatives of people with learning disabilities, selected at random by LAAS, generating a response rate of 33%, which is above average for a postal survey of this type.

## 5. Key Findings

- 5.1 We found little evidence that people with learning disabilities have withdrawn from, or reduced, their use of services as a consequence of the introduction of charges.

- 5.2 Most people asked to pay charges are doing so. Learning Disability Services report that collection rates are broadly on target in relation to housing support charges, while around 80 of the 100 people eligible to pay charges for day services are doing so.

- 5.3 Most people with learning disabilities rely heavily on someone else to manage their financial affairs. 83% of people with learning disabilities say they do not know what their weekly income is.

- 5.4 The introduction of charges generated concern amongst both service users and their carers.

69% of service users reported feeling “concerned” or “slightly concerned” when they first heard about the introduction of charges.

A higher proportion of carers (85%) reported that they were “concerned” or “slightly concerned” when they learned about the introduction of charges.

- 5.5 The level of concern about charges amongst service users has reduced over recent months. 43% of people with learning disabilities now say that they are “not at all concerned” about the charges. However, 28.5% of people remain “slightly concerned” and a similar proportion remains “concerned”.

- 5.6. Concern about the charges remains high amongst carers. 82% reported feeling “concerned” or “slightly concerned” when they first heard about the introduction of charges. Four months on the figure remains at 69%. The proportion of carers who say they are “not at all concerned” by the charges has increased from 15% to 31%.

- 5.7 The survey found mixed views on whether people should be asked to pay a charge for some community care services. 46% of carers felt that it was “not right” for charges to be made whilst the same proportion 46% felt that (reasonable) charges were acceptable. 8% of carers were undecided on the issue.

Opinions amongst service users were also fairly evenly split, with 37% of people expressing the view that charges were acceptable and 43% feeling that it was “not right” for charges to be made.

- 5.8 Most carers (77%) felt that if other people living in West Dunbartonshire (for example older people) were asked to pay for some community care services then people with learning disabilities should not be treated differently. A third of people with learning disabilities shared this view, although a further 20% were undecided.
- 5.9 There is little evidence that people with learning disabilities have had to change the activities that they do as a result of charges being introduced. 83% of service users reported that they had not had to make changes in the things they do since charges were implemented. Two carers reported that the person they care for had had to change the activities they are involved in, but only one provided a specific example.
- 5.10 People were asked for their views on local Learning Disability Services. Half of the carers surveyed said that Learning Disability Services in West Dunbartonshire have improved over recent years. A similar proportion felt they had “stayed the same”.

Amongst people with learning disabilities themselves, however, almost three quarters of those surveyed (74%) felt that services have improved. 60% of people said that, in their experience, Learning Disability Services have “improved a lot” with a further 14% saying they had “improved slightly”.

## **Introduction**

This report has been produced by Lomond & Argyll Advocacy Service in response to a decision by West Dunbartonshire Council to seek a review of charges for Learning Disability Services and their impact.

Section One of the report is based, largely, on background and statistical information provided by West Dunbartonshire Learning Disability Service.

Section Two, the bulk of the report, focuses on the views of people with learning disabilities living in West Dunbartonshire and their carers.

## **Background**

In August 2008, West Dunbartonshire Council implemented a charging policy for some Learning Disability Services.

This led to the introduction of charges, these are calculated at £3.00 per full-day for Day Centre/Services and £20.00 per week for Housing Support Services. No service user has been asked to pay both charges and where a person accesses both day services and housing support services the lower charge applies.

Approximately 175 people with learning disabilities living in West Dunbartonshire will be affected by the implementation of these charges. It is anticipated that charges will generate £123,000 per annum in income (at 2008/9 rates).

## **Remit of the Review**

Following the introduction of charges, Council agreed that a review should be undertaken to consider the impact of charges on service users and their carers. Council agreed that the review should consider the following:

- 1. Do service users “have sufficient means to lead a fulfilling and meaningful life”?*
- 2. What is the Council’s definition of “sufficient means to lead a fulfilling and meaningful life”?*
- 3. How can the above be assessed?*
- 4. The impact the charging policy has had on the service, including take-up.*
- 5. Whether constituents are now using other services as stated in the option appraisal.*
- 6. The views of service users and carers.*

*The review should include service users, carers and interest groups.”*

## **Independence**

West Dunbartonshire Learning Disability Services recognised that the process of consulting with service users and carers would be strengthened if it was facilitated by an agency which is independent of the local authority, thus minimising the possibility of any real or perceived conflicts of interest, which may, or may be seen to, influence the views of service users and carers.

### **Lomond & Argyll Advocacy Service**

Lomond & Argyll Advocacy Service (LAAS) was commissioned to undertake the review. LAAS is an independent advocacy provider working across West Dunbartonshire and has well-established links with people with learning disabilities. The service provided independent advocacy services to 27% of people with learning disabilities in receipt of council services last year. This represents the second highest uptake of independent advocacy in Scotland. The Service is a not-for-profit company and a recognised charity and is governed by a voluntary Board of Directors, which includes service users. Whilst agreeing its strategic objectives with commissioners, the service maintains its independence in all the work it undertakes.

## **SECTION ONE**

### **“A fulfilling and meaningful life?”**

In June 2008, the Manager of Learning Disability Services in West Dunbartonshire wrote to service users advising them of the introduction of charges for some learning disability services. The letter contained a commitment that it was the clear aim of the Council to ensure that people with learning disabilities continue to have “sufficient means to lead a fulfilling and meaningful life”.

Council asked the review to consider if service users “have sufficient means to lead a fulfilling and meaningful life” and how “sufficient means to lead a fulfilling and meaningful life” can be defined.

We asked the Manager of Learning Disability Services for his views. This is what he said:

***“The definition of “full and meaningful life” is from “The Same as You?” (2000): Scottish Government. This document is a key initiative in Learning Disability Services, which set the agenda for the development of future services following a wide-ranging Government review.***

***West Dunbartonshire Council has shown a clear commitment to meeting this objective by increasing the range of services available to adults with learning disabilities. This has included restructuring all housing support services to the extent that the council has no hostel accommodation, something which is seen by Government agencies as a positive step. In addition, we have increased the range of activities available to adults using our day services. People with learning disabilities now have a menu of services from which to choose, this includes Day Centres, Locality Services and Day Opportunities, all offering a wide range of community based services to meet individual needs.***

***The issue of sufficient means has been addressed through the maximising of individual benefits. The majority of adults with learning disabilities have had their benefits maximised and full use has been made of the Independent Living Fund (ILF), where the council is now first equal in the UK for its take up. Service users who are in receipt of ILF are able to recover the local authority charge from the Fund. This process is underway and will include all service users currently in receipt of ILF. Service users are encouraged and assisted to access a full range of benefits in order to increase their life opportunities.***

***With regard to charges, in all cases where a welfare rights visit and a financial assessment has taken place, no one has been assessed as being unable to pay the charge. In some cases, additional benefits have***



***been applied for where this has been appropriate. No one will pay both the day service and housing support service charge. Where people are in receipt of both services, only the housing support charge is payable.***

***Overall, the means to lead a fulfilling life can be best assessed by the quality of life that this provides for the person involved. As demonstrated above, this is best done by reviewing the range and quality of services which are available to adults with learning disabilities.***

***A key recommendation in “The Same as You?” should have a Partnership in Practice Agreement clearly outlining its aims and objectives for learning disability Services over a three year period. The Learning Disability Partnership in Practice Agreement 2007 – 2010 highlights our commitment to adults with learning disabilities and their carers. This is clearly evidenced in the carer only respite group which is overseeing the development of the new respite service in Clydebank. There is a strong commitment to consultation with an undertaking for an annual event which will provide an opportunity to review all services and developments within Learning Disability Services. The next such event will take place in January 2009.***

***Within the Partnership in Practice Agreement we have made a strong commitment to personalised services and independent living. This includes improving the employment opportunities available, further enhancing the economic resources available to adults with learning disabilities. We have increased the number of personal life plans and are in the process of developing a new self-directed care strategy. All of the above are underpinned by a year-on-year increase in the Learning Disability budget.”***

Council also asked the review to consider how “sufficient means to lead a fulfilling and meaningful life” can be assessed.

Identifying the myriad of factors that combine to create a “fulfilling and meaningful life” is no easy task although most people would accept that the level of a person’s income is one such factor. Although the best available evidence suggests that as many as 65% of people with a learning disability would like to get a paid job, the vast majority of people with a significant learning disability do not work and are reliant on benefits. This means that the average income of people with learning disabilities will be lower than that of the general population.

### **Income Maximisation**

The Convention of Scottish Local Authorities (CoSLA) have produced guidance on charging policies and many local authorities have developed income maximisation policies which operate alongside charging policies.

Income maximisation policies can help people pay charges while enabling service users to have a better lifestyle by ensuring they access the range of benefits to which they are entitled. Income maximisation also helps bring scarce resources into communities and helps people with learning (and other) disabilities meet the added costs arising from disability.

In addition to responding to specific requests, Learning Disability Services are currently reviewing the benefit entitlement of individual clients on a systematic basis.

In particular, Learning Disability Services have made efforts to maximise access to the Independent Living Fund (ILF). Prior to 1995 only 51 disabled people in West Dunbartonshire were in receipt of ILF. Since then uptake has more than doubled and currently stands at approximately 115. This dramatic increase in uptake is, in large part, due to the employment of a dedicated ILF worker within the Learning Disability Service.

Under existing regulations, people in receipt of ILF are able to offset charges made by the local authority against the contribution they make to the Independent Living Fund. This means that for recipients of ILF the introduction of charges has a neutral impact.

West Dunbartonshire Council operate charging policies based on financial assessment. This assessment is used to determine ability to pay. In any case where there has been an issue regarding the ability of a person with learning disabilities to pay the charges which have been introduced, they have been offered a visit from the Learning Disability Service Welfare Rights Officer. We are advised by Learning Disability Services that none of the visits carried out to date have resulted in an assessment that the person involved did not have the ability or the appropriate benefits to pay the charge.

## **Inclusion**

Clearly, there are many factors, other than income, which contribute to a “fulfilling and meaningful life”. People with learning disabilities tell us that they want to lead “ordinary” lives, to feel valued and to be included in the communities in which they live. West Dunbartonshire Council produces a “Partnership in Practice Agreement” setting out the future direction and funding of learning disability services. Over recent years the focus has been on supporting individuals to have a fully integrated life in their local community, accessing good quality, flexible support services aimed at ensuring the needs of service users and their carers are met.

## **Consultation and Service User Involvement**

“The Same as You?” (2000) made clear that it’s key aim of achieving greater social inclusion for people with learning disabilities should also be reflecting in planning processes and that people with learning disabilities and their carers should be involved in the planning and development of the services they use, both collectively and as individuals.

Learning Disability Services in West Dunbartonshire have supported a number of initiatives to support user and carer involvement and promote consultation.

The Good Life Positive Attitudes Group is a collective advocacy forum for people with learning disabilities in West Dunbartonshire. The Group produced their own version of a Partnership in Practice Agreement: *“Listening to the Voice of Experience – A Shadow PiP for West Dunbartonshire”* (2003/2007) and have continued to be involved in planning processes.

Greater access to independent advocacy services has supported more people to play a full part in the discussions and decisions which shape their lives. Scottish Government statistics show that the uptake of independent advocacy amongst people with learning disabilities in West Dunbartonshire is well above the national average and the second highest in Scotland.

The Partnership in Practice Agreement (2007/2010) also contains a commitment to an annual consultation event involving people with learning disabilities and their carers.

## **SECTION TWO**

This section of the review focuses on the views of people with learning disabilities and their carers.

### **The views of people with learning disabilities**

#### **Methodology**

The views of people with learning disabilities were sought via a number of “focus groups”, independently facilitated by Lomond & Argyll Advocacy Service, and through individual questionnaires. A total of 35 people with learning disabilities participated in the consultation.

Three “focus groups” were convened and hosted by established forums involving people with learning disabilities in West Dunbartonshire.

Elected Client Councils, independently facilitated by the Advocacy Service, are well established in both Dumbarton Centre and Auchentoshan Centre. Each Council consists of representatives elected by service users. Focus groups, convened by the Client Councils, met in both Dumbarton and Clydebank.

The focus group meeting in Dumbarton involved nine service users. Fifteen people attended the focus group in Clydebank. Workers from the Advocacy Service facilitated both meetings. Participants were provided with basic information about charges for learning disability service and, following an informal group discussion, each participant completed a short questionnaire. Questionnaires were designed with support from Learning Disability Service’s Speech and Language Therapist/Total Communication Worker.

In addition to the two focus groups described above, views were sought from members of the “Good Life – Positive Attitudes Group”. The group is a long established and well-respected collective advocacy forum for people with learning disabilities in West Dunbartonshire. The group seeks to provide a collective voice for people who use learning disability services locally and recently researched, produced and published “Listening to the Voice of Experience – A Shadow Partnership in Practice Agreement for West Dunbartonshire. This document represented the first ‘PiP’, or plan for learning disability services, written by people with learning disabilities themselves. The group’s work has attracted national attention and much praise.

Eleven members of the “Good Life – Positive Attitudes Group” offered their views on charges for learning disability services as part of the consultation.

The answers given to each of the questions we asked appear in the pages that follow, along with quotations from the comments made by people in their own words.

### **What people with learning disabilities told us:**

We began by asking people involved in our focus groups what services they were being asked to pay for. Some people (17%) were unsure or didn't know what charges they were being asked to pay. Uncertainty about the charges appeared higher amongst people in receipt of housing support services.

### **How much have you been asked to pay for learning disability services?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Day Centre/Services (£3 per full day)	<b>21</b>	<b>60%</b>
Housing/Home Support Services (£20 per week)	<b>8</b>	<b>23%</b>
Don't know	<b>6</b>	<b>17%</b>

It appeared that most people who were charged for day centre/service were aware of the charge, which was often being collected on a daily basis and involved service users making cash payments.

People in receipt of housing support services, on the other hand, are often supported to budget and manage their financial affairs by paid workers from a support provider organisation. Although charges may well have been explained to people they are likely to have less "hands on" involvement in the collection process, which is being administered, in many cases, by service provider organisations.

We then asked people about how much support they needed to manage their finances:

### **How much help do you need to manage your money?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
None, I manage completely independently	<b>5</b>	<b>14%</b>
A bit of help	<b>7</b>	<b>20%</b>
A lot of help	<b>7</b>	<b>20%</b>
Someone else manages my money for me	<b>16</b>	<b>46%</b>

Almost half of respondents said that someone else manages their money for them. It appeared that this was particularly true of people who received support from relatives/unpaid carers. Even people who appeared to have a good grasp of the concept of money often relied on other people to take charge of their finances.

***"I look after my own 'pocket money' but my dad pays for everything else".***

***"My sister buys me the things I need and gives me my lunch money every day".***

Next we asked people if they knew how much money they had coming in each week:

## Do you know what your total weekly income is?

Response	Number	Percentage
Yes, I do	5	14%
I'm a bit unsure	1	3%
No, I don't know	29	83%

The vast majority of people with learning disabilities (83%) said that they did not know their weekly income. Many people who relied on others to manage their finances did not appear to realise that it was their own money, which was being used to pay for things.

***“My mum and dad are pensioners. Three pounds is a lot of money for them to find everyday.”***

***“I get twenty pounds a week. I get it every weekend and I put it in my wallet.”***

We then asked how they felt about charges for learning disability services:

## How did you feel when you first heard about the introduction of charges for learning disability services?

Response	Number	Percentage
Concerned	17	49%
Slightly concerned	7	20%
Not at all concerned	11	31%

Almost half of the people we asked (49%) said that they were “concerned” when they first heard about the introduction of charges. A further 20% of people said they were “slightly concerned”. About one a third of people told us that they were “not at all concerned”.

Some of the people who said they were “concerned” went further and described feeling “angry” and “upset”. Some people’s concerns were about the impact of charges on their relatives or carers.

***“It makes me angry. This is our Centre – how can they charge us to come here?”***

***“I was upset. My sister said I might have to stop coming to the Centre.”***

***“My mum’s mad. She’s a pensioner and it’s a lot of money.”***

***“I thought I was going to have to choose £3 or the Centre or £3 for my line dancing.”***

Some of the people who told us they were “not concerned” also made comments:

***“It doesn’t bother me. I like to pay my way.”***

***“If I went into a shop with no money I wouldn’t get anything. If you want something you have to pay for it.”***

We then asked people how they feel about charges now, about four months after they were introduced:

**How do you feel now about charges for learning disability services?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Concerned	<b>10</b>	<b>28.5%</b>
Slightly concerned	<b>10</b>	<b>28.5%</b>
Not at all concerned	<b>15</b>	<b>43%</b>

The proportion of people who said they were “concerned” had fallen from 49% to 28.5%. However, more than half of the people we asked (57%) told us that they remained either “concerned” or “slightly concerned” about the charges. The proportion of people who said that they were “not at all concerned” had risen from 31% to 43%. Some people were unsure if the charges they are liable for have been paid.

***“Nobody has asked me for money, so I don’t know if I’m going to get a big bill.”***

***“I’m not as bothered as I was but I still don’t think it’s right.”***

***“I’m ok with it now – I don’t feel it’s affected me that much.”***

We went on to ask a question about the general principle of charges for community care services:

**Do you think it is right that people should be asked to pay a charge for some community care services?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>13</b>	<b>37%</b>
No	<b>15</b>	<b>43%</b>
Don’t know	<b>7</b>	<b>20%</b>

Opinion amongst people with learning disabilities was fairly evenly split. 37% of people thought that (reasonable) charges were acceptable, while 43% of people thought that it was “not right” to apply charges for community care services.

Next we asked:

**If some people living in West Dunbartonshire (for example older people) are asked to pay a charge for some community care services. Should people with learning disabilities be treated differently?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>17</b>	<b>49%</b>
No	<b>11</b>	<b>31%</b>
Don't know	<b>7</b>	<b>20%</b>

Some people found this a difficult question to answer and lots of people said that nobody should have to pay for the support services they need. Others felt very strongly that people with learning disabilities should be treated the same as everyone else, even if it meant having to pay charges.

***“I think everyone should be treated the same.”***

***“My mum has to pay for her care so why shouldn't everyone else? I get DLA (Disability Living Allowance) and that's to help with the support I need – it's not for buying things for the house.”***

***“We're always telling people we want to be equal – so that's it!”***

**Since the charges were introduced have you had to change any of the activities you do?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>6</b>	<b>17%</b>
No	<b>29</b>	<b>83%</b>

A large majority of people (83%) reported that they had not had to make any changes in the activities they are involved in since the introduction of charges. No one with a learning disability reported that they had reduced or withdrawn from services as a result of charges. Of those who did report a change in the activities that they do, only three people provided examples:

***“I don't think I go out as much as I used to.”***

***“I don't get as much money to spend in the café.”***

***“I'm can't buy some of the things that I want.”***

Finally, we asked people with learning disabilities how they felt about the services they use:

**In general, over recent years, do you think that learning disability services in West Dunbartonshire have:**



<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Improved a lot	<b>21</b>	<b>60%</b>
Improved slightly	<b>5</b>	<b>14%</b>
Stayed the same	<b>9</b>	<b>26%</b>

Almost three quarters of people (74%) said that, in their experience, services had “improved”. 60% of people felt that they had “improved a lot” and a further 14% felt that they had “improved slightly”. About a quarter of people thought things has “stayed the same”. Several service users raised concerns about the deterioration of the physical environment at the Auchentoshan Centre.

***“Things have got better for me. I go out more than I used to - go to more places. I feel more part of things.”***

***“ I like having my own flat. I used to have to share with people but now I’ve got my own place.”***

## **The views of carers**

### **Methodology**

The views of unpaid carers were sought by way of a postal questionnaire, sent to forty individual carers selected at random by Lomond & Argyll Advocacy Service.

To facilitate the selection of a random sample the Advocacy Service was provided with two anonymous lists of people with learning disabilities affected by the introduction of charges.

The first list comprised people who have been asked to pay a charge for “day services” (e.g. attendance at a day centre). The second list comprised people who have been asked to pay a charge for “housing support services”.

People on each of the lists were ranked alphabetically by service provider organisation but no individual names appeared on either list. A random sample of twenty people was selected from each list by the Manager of the Advocacy Service.

Where it transpired that an individual selected had no known carer another individual receiving support from the same service provider organisation was selected at random as a replacement.

Learning Disability Services then distributed questionnaires by post, along with an explanatory letter from the Manager of the Advocacy Service and a pre-paid stamped addressed envelope. Participants were asked to return completed questionnaires directly to the Advocacy Service.

Participants in the survey were asked to answer nine questions and also invited to make additional comments in response to each of the questions or on general points of relevance.

Participants were also invited to contact the Advocacy Manager by telephone if they had any queries or wished to make any further comments. Four carers made contact with the Advocacy Service by telephone or in person and their comments are incorporated into the report.

Each participant in the survey was given the option of providing contact details or remaining anonymous. The majority of participants provided contact details but a substantial proportion (46%) chose to return the questionnaire anonymously.

13 completed questionnaires were returned. This represents a response rate of 33%, comparatively high for a postal survey. It is generally accepted that those people who hold the strongest views or are most concerned about the relevant issue are most likely to respond to a postal survey of this type.

The answers given to each of the questions posed appear in the pages that follow, along with quotations from the comments made by people in their own words.

**What carers told us:**

We began by asking:

**How much has the person you care for been asked to pay for learning disability services?**

The responses we received are set out in the table below:

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Day Centre/Services (£3 per full day)	<b>8</b>	<b>62%</b>
Housing/Home Support Services (£20 per week)	<b>1</b>	<b>8%</b>
Don't know	<b>4</b>	<b>30%</b>

Although our sample contained an equal number of people affected by charges for “day services” and “housing support services”, a significantly higher number of responses were received from people affected by charges for “day services”.

Some people were unclear about what charges the person they care for is being asked to pay. This reflects the fact that carers involved in the study are likely to have varying degrees of involvement with the person for whom they care.

***“I am not a direct carer, but simply try to maintain an overview of my relative’s care by the Social Work Department.”***

***“Traditional Day Services did not meet my son’s needs so he already pays for day opportunities which suit his needs. He pays for this from his benefits.”***

***“This (Day Centre charges) works out at £15 per week or £690 over 46 weeks, allowing time off for holidays.”***

Next we asked:

**How much help does the person you care for need to manage their money?**

These were the responses we received:

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
None, they manage completely independently	<b>0</b>	<b>0%</b>
A bit of help	<b>0</b>	<b>0%</b>
A lot of help	<b>0</b>	<b>0%</b>

Someone else manages their money for them	13	100%
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Perhaps surprisingly, all of the carers who responded to the study said that the person they care for relies entirely on someone else to manage their money for them. This is borne out by the consultations undertaken with service users themselves. 88% of people with learning difficulties who participated in the study said that they “did not know” what their total weekly income is.

Although we did not ask whether any formal arrangements were in place to manage the finances of people who lack capacity to do so for themselves (under the Adults with Incapacity (Scotland) Act 2000), it seem likely that most arrangements are informal.

***“(My son) has no knowledge of money and cannot count as far as I am aware.”***

***“I am very happy for the person in charge where my cousin stays to deal with all money matters, they do it very well.”***

***“Money is given on a daily basis as needed.”***

Turning to the introduction of charges, we then asked:

**How did you feel when you first heard about the introduction of charges for learning disability services?**

The responses we received are set out below:

Response	Number	Percentage
Concerned	7	54%
Slightly concerned	4	31%
Not at all concerned	2	15%

The vast majority of carers said that they felt “concerned” or “slightly concerned” when they first heard about the introduction of charges for learning disability services. Only 15% of respondents said that they were “not at all concerned” at all when they heard about the introduction of charges.

One carer raised concerns about the lack of notice given to carers regarding the introduction of charges and another raised the issue of consultation

***“Carers were just informed in July, two weeks before the charges started on the 1<sup>st</sup> of August.”***

***“My concern was with the lack of consultation before this was put in place.”***

We then went on to ask:

## How do you feel now about charges for learning disability services?

People responded in the following way:

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Concerned	<b>6</b>	<b>46%</b>
Slightly concerned	<b>3</b>	<b>23%</b>
Not at all concerned	<b>4</b>	<b>31%</b>

Most of the respondents who said that they were “concerned” when they first heard about the introduction of charges reported that they remained “concerned”. One person who reported that they were initially “concerned” reported that they are now “not at all concerned”. Another person who said that they were “slightly concerned” when they first heard about the introduction of charges also reported that they were “not at all concerned” now.

The proportion of people who said that they were either “concerned” or “slightly concerned” about charges has fallen from 85% to 69% but remains high. The proportion of people who reported being “not at all concerned” has increased from 15% to 31%

Some carers commented on the impact the charges have had:

***“It (the charge) means there is less money I can save from (my son’s) account for his future.”***

***“With food, gas and electricity services increasing it is getting harder to manage.”***

***“I am happy...as long as charges are not too much and people can afford it.”***

Some people expressed concerns that charges may rise in the future and that their introduction is “the thin end of the wedge”.

Others offered their comments relating to consultation with carers on the introduction of charges:

***“It would have been helpful to be involved in a consultation process regarding the implementation of these payments.”***

***“The fact that carers are being given the opportunity to fill in this questionnaire is positive!”***

We then asked a more general question:

**Do you think it is right that people should be asked to pay a charge for some community care services?**

On this point opinion was very evenly split:

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>6</b>	<b>46%</b>
No	<b>6</b>	<b>46%</b>
Don't know	<b>1</b>	<b>8%</b>

Some people expressed the view that all community care services should be free at the point of delivery, drawing comparisons with education or health services. Others appeared more comfortable with the issue of charges for some community care services

***“I think some people can afford to pay something towards the cost of the service and some can’t. This depends on whether they receive basic allowances/benefits from the state only or whether they have been provided for in the wills of parents/family.”***

Historically, there are some anomalies in how charges for community care services have been applied, partly due the legislative framework under which such services have been provided and the ability (or otherwise) of local authorities to implement charges. Some client’s (for example older people) have, sore some time, undergone a routine financial assessment to determine their liability for a financial contribution. Services for other client groups, including people with learning disabilities, have until recently, been exempt from charges.

We asked our sample of carers:

**If some other people living in West Dunbartonshire (for example older people) are asked to pay a charge for some community care services, should with learning disabilities be treated differently?**

These were the responses we received:

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>3</b>	<b>23%</b>
No	<b>10</b>	<b>77%</b>
Don't know	<b>0</b>	<b>0%</b>

The responses indicate that most people believe people with learning disabilities should be treated the same as everyone else.

A number of people, with differing views, added their comments:

***“Most adults with learning disabilities are on ‘means-tested’ benefits. The biggest majority of carers with adults at Auchentoshan are all pensioners themselves.”***

***“As a parent I feel I do not want my son to be seen as “a charity case” or a “poor wee soul”. He is a young man who enjoys lots of different activities, which he is able to pay for due to the amount of benefit he receives.***

***I also feel if there is to be true inclusion of people who are disabled in some way, that paying for services as the rest of the general public have to do, helps in the process of inclusion.”***

***“Everyone, no matter how they are “labelled”, should only make a contribution to services if they have enough money left over after their needs are met.”***

We tried to find out if the introduction of charges had had an impact on the activities that people with learning disabilities are able to participate in:

**Since the charges were introduced has the person you care for had to change any of the activities you do?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Yes	<b>2</b>	<b>17%</b>
No	<b>10</b>	<b>83%</b>

One person said that they were still unsure about this. Two carers reported that the person they care for had had to change the activities that they take part in, but only one provided a specific example.

***“...even although we are pensioners we are liable to pay the charges. My son is completely dependant on us... we have cancelled his visits to the Adult Centre as we feel so strongly about these charges.”***

Some people suggested that charges might have an impact, in the longer term, on a peoples’ ability to pay for things like holidays.

Finally, we asked a general question about how people view developments in learning disability services locally:

**In general, do you think that learning disability services in West Dunbartonshire have:**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
Improved a lot	<b>4</b>	<b>33%</b>
Improved slightly	<b>2</b>	<b>17%</b>
Stayed the same	<b>6</b>	<b>50%</b>

Half of the carers who responded felt that services for people with learning disabilities in West Dunbartonshire have improved over recent years. A third of respondents felt that they had “improved a lot”.

Two of the carers who felt that services had not improved made reference to the deterioration of the physical environment at the Auchentoshan Centre. One carer felt unable to comment on the wider picture but praised the services their own relative receives:

***“I find the service my relative receives to be caring, safe, friendly and of a very high standard”***



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